

The Difference We Need To Make – A summary of our New Dementia Strategy: Everyone’s Story



EVERYONE'S STORY

- 90,000 people in Scotland live with dementia. Of those, over 3,000 are under the age of 65 and some estimates suggest that 1 in 3 people born today will go on to develop dementia.
- Dementia is now recognised as a global health priority that affects everyone, as individuals, family members and citizens of our communities. We therefore view this strategy as 'everyone's story'.
- Building on our world leading policy commitments, this strategy sets out a long-term vision for change to meet the needs of people living with dementia and their care partners/ unpaid carers.
- This summary sets out the difference we want to make. This includes:
 - » Recognising dementia as a condition of the brain that affects the whole person, while upscaling efforts to address its mental health and wellbeing impacts
 - » Ensuring services and supports are dementia-inclusive and create environments which enable people with dementia to live their best possible life

- » Deliver equity of access to information, treatment, care and support for people living with dementia
 - » Uphold a person's human rights throughout their dementia journey
 - » Ensure people are supported by a skilled, knowledgeable and trauma-informed workforce.
- We will work to deliver these and our other ambitions through a series of 2-year delivery plans, the first of which will be developed by the end of 2023.

HOW WE GOT HERE?

This strategy builds on a strong track record in dementia policy and practice. This was added to by a series of conversations that embraced communities up and down Scotland, listened closely to professional and academic voices, and placed the experiences of people living with dementia at its core.

It has been developed in collaboration with the National Dementia Lived Experience Panel, established in 2022. Alongside the Strategy Advisory Group, the Panel has a formal governance and accountability role, working with government to oversee the strategy's development. Providing a national governance role for the Panel is a major change from previous strategies, and has been critical to the 'new story' set out.

In addition to our governance partners, we have engaged people across Scotland through:

- 8 months of engagement, including an initial National Conversation open to everyone with an interest in dementia.
- 110 engagement events and discussions in person and online, from Orkney to Dunoon.

- 167 written responses to our National Conversation from individuals, care providers, communities and stakeholder organisations.
- A parliamentary debate on the Strategy, informed by a summary of What People Told Us during the National Conversation.
- A series of discussions with senior leaders in local and national government, including at COSLA's Health and Social Care Board.
- A specific focus on capturing the experiences of our minority communities in relation to dementia care and support, which has informed the Strategy's development and will be a central part of delivery.
- Multiple sessions with practitioners and academics, as well as commissioning an international evidence review on dementia policy interventions.

OUR VISION

“Our vision is of a Scotland where people living with dementia and their care partners have their strengths recognised, their rights upheld, and are supported to live an independent life, free from stigma and with person centred treatment, support and care when and where they need it.”

Underpinning this vision is a recognition that people living with dementia and their care partners/unpaid carers are experts by experience and are best placed to know what they need and when they need it. Support to develop this expertise can help avoid stress, struggle and the growing sense of loss that a dementia diagnosis can bring.

Acknowledging the expertise of lived experience reflects both our human rights principles and our focus on person-centred support which places the person at the centre, as an expert in their own experience.

The Difference We Want To Make

- 1 Dementia is recognised in public health and in practice as a disease of the brain that affects a person's whole life and those close to them. Diagnosis can bring significant mental health and wellbeing challenges that need to be acknowledged and addressed to ensure a person's rights are upheld.
- 2 Policy makers, support and service providers, communities and society all have an understanding of dementia, including the importance of prevention and early detection, and are inclusive of people living with dementia, able to engage and respond confidently and appropriately, creating environments that enable people to live well with dementia.
- 3 People living with dementia and their care partners have equity of access to high quality, information and advice, evidence-based treatment, care and support when and where they need it, including dementia-specific palliative care, and have access to practitioners with knowledge and skills of appropriate dementia care.
- 4 The human rights of people living with dementia and their care partners are upheld throughout their dementia journey.
- 5 People are supported by a skilled and knowledgeable workforce that accesses the highest quality dementia specialist education and training and implements evidence based, including trauma-informed, practice.

A MORE CONNECTED EXPERIENCE

The strategy follows the experience of dementia from a person's perspective. It starts with information and awareness around dementia, through to diagnosis, living the best possible life, support for advanced dementia and end of life care. It also recognises the stigma a dementia diagnosis still carries, and the need for this to change.

Challenging stigma

- **The Challenge** – Recognising and addressing how stigma affects our perceptions and understanding of dementia, from the language we use to the value we place on the contribution people living with dementia and their care partners/unpaid carers can make.
- **The Difference We Need To Make** – People have a greater awareness and understanding of dementia, and fears around seeking a diagnosis are addressed.

Brain Health

- **The Challenge** – Building on our world-leading Brain Health & Dementia Research Strategy to expand population public health awareness and literacy about brain health.

- **The Difference We Need To Make** – People are given the tools and knowledge to better understand their brain health and potential risk factors for some dementias. This includes through public and school education, as well as working with Scotland’s research and academic communities.

Diagnosis

- **The Challenge** – Delivering a person-centred, rights-based, accessible, timely and uniform diagnosis process, adaptive to a person’s needs
- **The Difference We Need To Make** – People have access to a diagnosis in their localities through a process that recognises their preferences and needs, alongside enhanced emotional support and a treatment plan with regular monitoring.

Post Diagnostic Support

- **The Challenge** – To deliver on our flagship policy of a minimum of 1-year Post-Diagnostic Support for all who need it, when they need it, extending its reach and how it is delivered.
- **The Difference We Need To Make** – People diagnosed with dementia access appropriate Post-Diagnostic Support in a setting in which they are most comfortable, irrespective of their location, age or stage of dementia.

Living the best life possible

- **The Challenge** – Ensuring support for people living with dementia in their communities is of a high quality and is focused on enabling them to live well at home.
- **The Difference We Need To Make** – People are supported to live actively in their community, with an enhanced range of community networks and spaces, have access to co-ordinated care, and are informed around how to make adaptations to their home to remain in their setting of choice as long as possible.

Advanced dementia

- **The Challenge** – Ensure the right support and care is available on a day to day basis for the growing number of people with advanced dementia, adaptive to individual need (including any difficulties in communication and understanding others), regardless of the severity of need or whether they are living in their own home, are in hospital or in a care home setting.
- **The Difference We Need To Make** – Staff working across care settings access specialist training to meet the needs of people with advanced dementia, and people living with advanced dementia and their care partners are supported through established and integrated care pathways which step up the intensity and type of support as needed.

Caring

- **The Challenge** – Ensuring all unpaid carers have their contribution and expertise valued, with the right support for their needs as embedded in legislation.
- **The Difference We Need To Make** – People providing care and support for someone living with dementia can access appropriate support for their own health and wellbeing, and are provided the necessary information and support to make the right adjustments to support themselves and the person they are caring for.

Supporting Policy into Practice through Education, Training and Implementation Support

- **The Challenge** – Ensuring we have a workforce equipped with the necessary specialist knowledge, understanding and diversity of professional expertise to provide person-centred information, treatment, care and support for people living with dementia, meeting their needs while upholding their human rights.
- **The Difference We Need To Make** – The ‘dementia workforce’ accesses specialist education and training, benchmarked against the Promoting Excellence Framework, and is supported to implement best practice across all settings and professions.

HOW WE WILL DELIVER

- **Building on progress already made** – Starting from a strong base, this strategy is designed to build on the wide range of evidence-based approaches already in place in Scotland. It will embed what has had a positive impact, while also supporting us to evaluate and identify where change is needed.
- **Collaborate and deliver on these long term aims** – With partners, we will develop 2-year delivery plans, starting from the end of 2023. This will focus resources and hold us all accountable for realising the vision and ambitions this strategy sets out.
- **Continuing to empower the voices of lived experience** – Building on the work to develop this strategy in partnership with our National Dementia Lived Experience Panel, we will continue to support the Panel, alongside our Strategy Advisory Group, to be a critical governance partner in how we deliver on the ambitions they have helped us develop.

- **Addressing the experiences of our minority communities** – Through the lifespan of this strategy, we will have an enhanced focus on equalities issues, working with others to help to minimise the structural barriers to participation, diagnosis, treatment, support and care, regardless of ethnicity, race, sex, gender reassignment, sexual orientation and additional disability or neurodivergence. We include a focus on economic disadvantage and the specific issues for remote and rural communities.
- **Using our investment wisely** – In a challenging financial context, and recognising the importance of community to people living with dementia, we will use the Strategy’s ambitions to evaluate where we are investing in dementia treatment, care and support, with a focus on “upstream” investment in community settings to support people to live their best possible lives in their communities. This will be set out in our subsequent delivery plans.



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